

KinSys: A Database Management Application

Constance Johnson, RN, BSN^{1,2}, ¹University of Texas, Houston, TX, and Christopher Amos, MS, PhD², ²The University of Texas M. D. Anderson Cancer Center, Houston, TX.

The first step in assessing genetic risk for an hereditary cancer syndrome is to determine the family history of cancer. Family history information of first, second, and third degree relatives is crucial to accurately identify families that may be predisposed to cancer. These data can be collected through a self-administered questionnaire with a simple easy to read format or by interview with a clinical staff member. The direct interview method presumes that these individuals will be very knowledgeable about the health history of their entire family. The self-administered questionnaire, however, can be mailed to the individual prior to their appointment, which will enable them to contact family members and provide a complete and accurate family health history. In our institution, these questionnaires are mailed to the patient, completed, and mailed back to the clinic before the patient's appointment. A computer-generated pedigree is thus printed and ready for direct review with the patient at time of their appointment.

The creation of a pedigree or family tree provides a visual depiction of biological relationships and disease status to assist the clinician in identifying patterns of inheritance within a family. Since pedigrees are composed of symbols and text, hand-drawn pedigrees can present problems with inconsistency in the nomenclature and legibility. Computer generation of pedigrees addresses both of these issues. Although there are many commercially available pedigree drawing programs, very few have successfully combined the full functionality of a relational database with easy data storage, manipulation, and retrieval, along with a pedigree drawing component.

In 1997, UTMDACC developed Kinsys[®], a database management application specifically designed to complement a breast cancer genetics study. The application combined MSAccess 97 to construct the back-end database, with MSVisual Basic 5.0 to construct the front-end interface, and Cyrillic 2.13 (Cherwell Publishing, Inc., UK) for pedigree drawing. The system requires an IBM compatible computer, Windows 95 or NT 3.51 or higher, 16 MB of RAM, MSAccess 97, and Cyrillic 2.1. To download a free copy of this application, see <http://www.epigenetic.org>.

The Kinsys[®] system includes four main components, the data entry interfaces, pre-defined reports, data editing screens, and a pedigree drawing program. Since Kinsys[®] uses MSAccess 97,

innumerable family members can be directly related to each proband (or individual who initially comes for genetic counseling). The cancer and medical history interfaces allow multiple cancers and medical problems to be entered for each family member. Kinsys[®] automatically generates ICD9 codes for each condition entered from a list menu. These interfaces provide lists for ease of data entry, are Y2K compatible, and provide automatic coding for unconstrained data searches.

The Kinsys[®] edit menu allows the user to view entire families in a spreadsheet format that lists all of the family demographic or cancer/medical history information on one screen. Full editing of individual family members can be directly made in this area.

The pedigree drawing program is accessed through the main menu and the touch of a button. Proband and accompanying family history information are selected from a list box and are imported into Cyrillic 2.13. The symbols used in these pedigrees are standard; however, the shading of each symbol reflects this institutions practitioner preference. The shading according to the clinician's request has been placed in the source code so is automatically generated when these data are imported into Cyrillic. However, Cyrillic allows full editing of every symbol. The pedigree is capable of showing under each symbol that represents a family member, the individual's name, family identification number, birth and death dates, and up to 5 cancers and/or medical diagnoses. However, any one of these items may be omitted according to the needs of the clinician. Due to space constraints, the cancer and medical diagnoses have been coded into three character codes. For example, malignant breast cancer is always shown as MBR.

This database management application is located on a network drive to allow multiple users easy access to the database at any time. However, for security purposes, only the network administrator under the direction of the project manager can give privileges for use of the application.

Kinsys[®] has evolved over the past year to include genetic studies of families with gastrointestinal disorders. These databases are providing practitioners with more readable, consistent, and complete pedigrees for the chart record, a source of information for future genetic studies, and improved ability to see information at a family level, therefore better understanding the risk to each family member. (Partially supported by NIH Grant RO1CA70759)